

# **SUPPORTING FAMILIES IN FIRST PSYCHOTIC EPISODE**

Literature review

Liinu Peltomäki

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JYVÄSKYLÄN AMMATTIKORKEAKOULU  
JAMK UNIVERSITY OF APPLIED SCIENCES



## Description

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<p>Abstract</p> <p>The aim of this study was to examine how families could be supported when a family member is having the first episode of a psychosis. The study aimed at finding practical work methods for psychiatric nurses and other health care providers working with families where one member is experiencing the first psychotic episode. The purpose of this study was to provide evidence-based information for practical use.</p> <p>This study was carried out as a literature review. After defining the inclusion and exclusion criteria, the literature search was conducted in several databases (CINAHL, EBSCO, PubMed) and manually based on the reference lists of the chosen articles. A total of eight articles were relevant according to the criteria and content. These eight articles were analysed by using simplification, grouping and abstraction.</p> <p>Results concerned family centered attitude among professionals. Families experiencing first psychotic episode hoped that professionals would be accessible, supportive, informative and helpful towards all the family members. Needs of the family members should have been observed individually since support needs of the siblings and carers vary from each other.</p> <p>Results also brought out concrete psychoeducational methods which can be used to support families. Families have found that different kind of psychoeducational groups are good form of support. Importance of knowledge and education in traditional face-to-face contact but also by providing written information and using modern methods as DVD or online as a help, was highlighted. Also meeting others in the same situation and feeling the mutual support was experienced to be helpful. Sharing experiences helped families to gain new perspectives, information and understanding but also it decreased the family burden.</p>		
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<p>Tiivistelmä</p> <p>Tämän opinnäytetyön tavoite oli tutkia kuinka perheitä voidaan tukea perheenjäsenen sairastuttua ensipsykoosiin. Opinnäytetyö pyrki etsimään käytännön läheisiä keinoja psykiatrisille sairaanhoitajille ja muille terveydenhuollon ammattilaisille, jotka työskentelevät ensipsykoosiin sairastuneiden perheiden kanssa. Opinnäytetyön tarkoituksena on tarjota näyttöön perustuvaa tietoa käytännön tarkoituksiin.</p> <p>Opinnäytetyö toteutettiin kirjallisuuskatsauksen muodossa. Sen jälkeen kun sisäänotto- ja poissulkukriteerit oli määritetty, toteutettiin aineistohaku tietokannoista (CINAHL, EBSCO, PudMed) ja manuaalisesti valittujen artikkelien lähdeluetteloista. Yhteensä kahdeksan artikkelia vastasi kriteerejä ja oli sopivia sisällön perusteella. Nämä kahdeksan artikkelia analysoitiin yksinkertaistamalla, ryhmittelemällä ja abstrahoimalla.</p> <p>Tulokset käsittelivät perhekeskeistä asennetta ammattilaisten keskuudessa. Perheen kokiessa ensipsykoosia he toivoivat ammattilaisten olevan saatavilla, tukevan, antavan tietoa ja apua kaikille perheenjäsenille. Perheenjäsenten tuen tarvetta tulisi tarkastella yksilöllisesti sillä sisarusten ja huoltajien tuen tarpeet eroavat toisistaan.</p> <p>Tulokset myös toivat esille konkreettisia tapoja, joita voi käyttää perheen tukemiseen. Perheet ajattelivat, että erilaiset psykoedukationaaliset ryhmät ovat hyvä tuen muoto. Tiedon ja opetuksen tärkeyttä paitsi perinteisessä vuorovaikutuskontaktissa kontaktissa, mutta myös kirjallisessa muodossa ja hyödyntäen moderneja tapoja kuten DVD:tä tai internetiä, korostettiin. Myös toisten samanlaisessa tilanteessa olevien tapaaminen ja keskinäinen tuki koettiin hyödyllisiksi. Kokemusten jakaminen auttoi perheitä saamaan uusia näkökulmia, tietoa ja ymmärrystä, mutta myös vähensi perheen taakkaa.</p>		
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# 1 Introduction

Mental health is an essential part of overall health and wellbeing. WHO describes mental health in the following way: “Mental health is a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community.” Mental health is not only absence of mental health disorder but also positive resource in life and ensemble of several psychological, biological and social elements. (WHO 2014.) Mental health can be seen as resource which we are both using and gaining in different life situations. It is not unchangeable or stable during the whole human life but it is developing and varying while we grow and face different kind of life situations. (Lönnqvist & Lehtonen 2014, 30-33.)

The borderline between mental health and mental illness is surprisingly unclear and open to interpretations. People are not either totally healthy or totally sick. Everyone's mental health will face some challenges during life but that does not automatically mean any psychiatric diagnosis. Mental health problem causes subjective suffering, decreased ability to function and poorer quality of life by forming different kind of syndromes. (Lönnqvist & Lehtonen 2014, 31-32, 19-20.)

Family is an essential part of psychiatric nursing. It should be taken into consideration when preventing diseases and promoting health but also when someone in the family gets ill. In that situation it is important to survey the need of help and support in whole family, no matter if the one getting ill is a parent or a child. Some health problems have tendency to move from generation to other, and stay in the family, which makes family interventions even more important. (STM, 2012.) In spite of everything, family focused care has been in a background for a long time before it actually could be seen in practice (Alanen 2009, 5).

In onset of psychosis the family should be taken into consideration. Psychosis affects not only the family member having it but the whole family. Psychosis can be seen as a crisis for the family – feeling of safety and surety suddenly decreases. (Katajamäki 2009, 271.) According to Addington and others (2005) different kind of family interventions support the one having the psychosis but also the whole family. For example, according to many researches psychoeducation seems to increase family's knowledge and decrease the stress related to difficult situation (Napa et al 2014). From the ill family member's perspective Birchwood and Fiorillo (2000) are stating that family and individual interventions can shorten treatment period, help with gaining remission and decrease the risk of relapses.

Nurses and other health care providers are working with people having their first psychotic episode and their families in psychiatric wards and outpatient care but also in other health care settings. The aim of this thesis is to search how family can be supported when family member is having first episode of psychosis. This thesis is implemented in form of literature review and as a part of nursing studies.

## 2 Psychosis

### ***Prevalence***

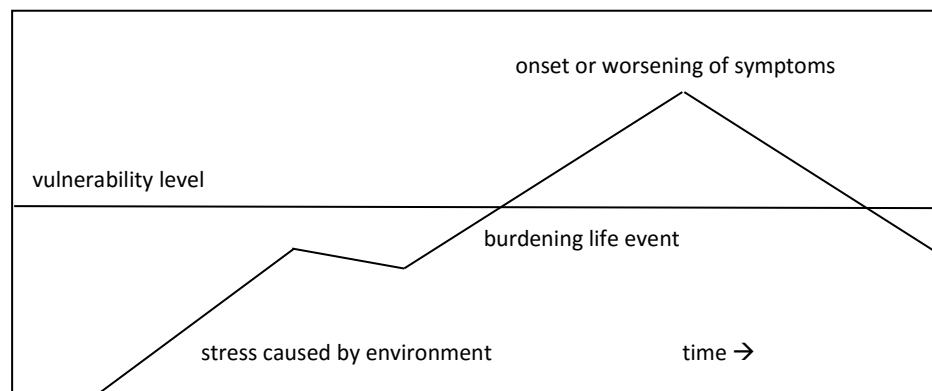
Population survey Terveys 2000 (made 2000-2001) aimed to research wellbeing and health of the Finnish people and as a part of this survey the occurrence of psychosis in Finland was researched. Appeared that occurrence of all kind of psychosis in Finland is 3,5%. Most common psychotic disorder was schizophrenia with 1% occurrence. Hereby psychotic disorders are challenge for public health also. (Suvisaari et al 2012.)

### ***Vulnerability***

There are many possible reasons why one might be more vulnerable of getting psychotic symptoms than other. Often there is no simple explanation but getting ill is sum of multiply reasons. Complications and developing disorders during the pregnancy and delivery might be a predisposing risk factor as well as heredity. Also environment and different kind of life situations might increase the risk of psychosis. Drugs, especially cannabis, can also defuse it if person is somehow vulnerable. Reasons are always individual and multifold. (Mielenterveystalo.)

Onset of psychosis or any other mental health problem can be pondered based on stress-vulnerability model. Basis for this model is that every person getting ill has some kind of vulnerabilities (as heredity or traumatic experience) and life situation which causes subjective stress (as loss of job or relationship problems. When combination of these two is too massive, person will have mental health problems. Each person also has individual protective factors as hobby or good interaction skills, which release the stress and prevent illness. Based on this model it is possible to ponder what kind of factors caused mental health problems in individual level. (Kuhanen et al 2013, 23-24.)

Figure 1. Stress-vulnerability model (Kuhanen et al 2013, 24.)



### ***Symptoms***

Shortly, psychosis can be described to be disturbance of reality sense and decreased ability to function but actually psychosis as a concept is really wide. First of all, psy-

chosis can be related to several different psychiatric and somatic disorders or, for example intoxicants and medicines. Organic psychosis are caused by somatic disease, intoxicants or medicines. Functional psychosis, on the other hand, are describing incipient mental illness. Psychosis can be very acute and last for a short time but it might also be one the first signs of beginning mental health disorders such as schizophrenia, delusional disorder or psychotic mood disorder. (Moilanen 2013.)

Common symptoms of psychosis are hallucinations, delusions and referential ideas. (Huttunen 2014a). Hallucinations are sensations without actual stimulus - seeing, hearing or somehow sensing something unreal what others can't notice. Typical example of hallucination is commenting voice. Psychotic person can't separate this false sensations from the reality. (Huttunen 2014b.) The content, target and extend of delusional symptoms varies between people experiencing them but common for all is that they are unrealistic beliefs. Still, cultural and religious beliefs should be separated from the delusions. Delusional person might believe someone is following him or that he is god, for example. Referential idea is one kind of delusion in which person is giving subjective, delusional meanings for everyday events. (Huttunen 2014c.)

Variety of different kind of psychotic symptoms can be divided into two categories; positive and negative. Positive symptoms are something additional as hallucinations, delusions, sporadic speech and actions while negative symptoms are affecting to the mood and normal actions. Example of negative symptom could be dullness, antisocial behavior or flagged feelings. (Mielenterveystalo.)

### **Stages**

Psychosis can be divided into three stages; prodromal symptoms, active stage and recovery. Prodromal symptoms are often nonspecific and not clearly connectable to proper psychotic symptoms. (Orygen youth health 2002.) This typical warning signs can include: social isolation, problems with clear thinking, concentration or memory, suspicious thoughts, anxiousness, increased tension, irritation or depression, unusual



energy level and changes in sleeping or in appetite. (CAMH.) This warning signs should be taken seriously especially if they are new and getting worse or if there has been psychosis in immediate family (NAMI). At the active stage of psychosis different kind of positive symptoms as hallucinations are in a main role. Person is also having problems with organizing his thoughts and expressing himself. (Orygen youth health 2002).

As psychosis itself also recovering from it is individual. Some are having psychosis only once but some are facing relapses later on in their lives. Anyway, it is important that person is actively involved in his own recovery. For example information about the topic and treatment in use is important for the person himself as well. Knowing and recognizing early warning signs might also help to catch next beginning psychotic episode at the early stage. Fostering a positive mental health and safety net is also desirable. (CAMH.)

### ***Treatment and rehabilitation***

Depending on situation, psychosis can be treated in outpatient care or in hospital. If patient is clearly in need of hospital care but not compliant to that, might person be treated in hospital against his will based on Finnish law of mental health. Risk of coercive treatment is that it might assist patient's negative attitudes towards treatment and help seeking in the future. (Moilanen 2013.)

Important part of treatment of psychosis is medication. In the early stage medication is aiming to decrease positive symptoms but in a long run it is important that medication helps negative symptoms as well. Medication often continues months or years after acute psychosis and some need antipsychotic medication for the rest of their lives. There are typical and atypical antipsychotics and both are still used. It is known that antipsychotic medications with the exception of clozapine, are equally effective. If person is having good experiences of some medicine it usually is favored. On the other hand, different kind of negative experiences, side-effects and high price decrease the will of taking medicines. In addition to antipsychotic medication also anxi-

olytics can be used for a short periods of time to relieve anxiety. All possible changes in medication should be done under the supervision and guidance of the physician. (Huttunen, 2008.)

Treatment and rehabilitation often go hand in hand. The weight of rehabilitation is in outpatient care but sometimes longer rehabilitation periods in hospital are needed. The care plan for treatment and rehabilitation is made individually. Presence of family and other close people in the process improves the results of rehabilitation. Psychoeducation and different kind of individual-, group- and family meetings are essential forms of support. Also different kind of functional groups and therapies might help person who had experience psychosis. Relative to ensemble it is also important to take into consideration things such as housing, studying and subsistence. (Mielen-terveystalo.)

### ***Special characteristics of first psychotic episode***

First psychotic episode refers to first psychotic breakdown person is having. Most commonly the first episode appears in young adults but it is possible in any stage of life. (NAMI.) Year 2011 National Alliance on Mental Illness (NAMI) carried out a survey about first episode of psychosis. Responders were people who have had psychosis themselves or witnessed early stage of psychosis. Results of the survey showed that the average age for first psychotic symptoms was 24 but still age range of survey varied between 3 – 63 –year-old. (NAMI 2011.)

Psychosis as a symptom is not unambiguous but it can be related to multiple different disorders or situations. At first, it is often difficult to say what type of psychosis person is experiencing and because the reason of first psychotic episode is usually unclear, person must be examined thoroughly to discover both somatic and psychiatric reasons behind the symptom. Essential information about the person and his situation should also be gathered for more specific treatment. Discussion with person himself and with his family helps with building overall picture about the current situ-

ation. Then for example blood tests and brain scan can help picturing somatic point of view. (CAMH.)

Onset of psychosis is new and frightening things especially in the first time person is having. Feelings of shame are often present. Additionally, strong prejudices and negative attitudes are still related to psychosis. For this reasons it is possible that seeking help is delayed although early intervention would have positive influence. (NAMI.) Help seeking might be delayed also because of unawareness, underestimation of the problem or not noticing problem at all (CAMH).

Treatment of first psychosis is important to start as soon as possible after the symptoms appear. Prolonged psychotic symptoms and delayed treatment reduces the prognosis. Often psychosis is noted in primary health care but the more specific diagnosis and treatment of the first psychotic episode is done in special health care. (Skitsofrenia: Käypä hoito -suositus 2015.) In her doctoral thesis Kilkku (2008) presents that according to National Institute of Clinical Excellence (2002) treatment of first psychotic episode can include combination of psychological and social interventions, pharmacotherapy, psychoeducation and interventions maintaining ability to work.

Medication treatment might differ from the treatment of multiple psychosis; in some cases there is need for antipsychotics only 6-24 months after symptoms disappear. Medication treatment can still be prolonged if there is some stressful life event in the near future such as divorce. In some cases it is still better to continue antipsychotic treatment as a preventive treatment and maintenance therapy. Example of that kind of case might be a person who is having family history of repeated psychosis. (Huttunen 2008.)

### 3 Families experiencing mental health problems

Family is an important unit of society. In book *Family-Focused Nursing Care* Denham and others (2015) define family in following way: "The word family refers to two or more people related biologically, legally, or emotionally." In a modern world family can also be seen as unit which has defined themselves as a family and takes care of each other. (Denham et al 2015, 26-27.) From a statistic point of view Statistics Finland defines family to be cohabitant, married or registered couple with or without children or one parent with children.

Idea of definition of a family has changed in time and old traditional conceptions have made way for new wider family definitions. Cohabitation, rainbow families, high divorce rates and multicultural relationships are examples of contenders of traditional family ideas. Before family could simply been seen as different sex couple with their children, so called nuclear family. Meaning of family is also difficult to define internationally because there are so many differences between cultures. (Denhan et al 2015, 10-11, 26.)

From nursing point of view it is important to provide high quality treatment for anyone without letting own thoughts and attitudes to affect it. It is not needed to renounce own opinions but respectful attitude towards patients with different kind of families is emphasized. (Denham et al 2015, 153.)

#### 3.1 Influences of mental health problems to the families

Mental illness in family affects the whole family. For them it is a usually unexpected and unwanted crisis. Getting ill has an influence to everyday life and actions but also to communication between family members. (Koskisuu & Kulola 2005, 13-19.) Family is an important social network for people and it has an influences individual's health, getting sick and recovering from the sickness. Individual affects to the family and

family affects to individual. Problems of family might cumulate and affect to generations one after the other if problems are not intervened. (Larivaara et al 2009, 20-21, 32.)

Mental health problem might have symptoms and affect family life already before its onset but untowardness makes it difficult to link early warning signs to actual mental disorder. Nonspecific symptoms can be connected to stress, for example. Person can notice some changes in his own behavior and feelings but thinks that it transient. Other family members might try to fix the changed situation by changing and adjusting their own behavior in new kind of situation. It is possible that family tries to hide the problem which is too difficult to understand, to protect family's normal functioning. After all, hiding a problem can be a bigger problem than problem itself. Juggling act with new, weird situation makes family blind to their own distress. At worst the situation is not realized until something extreme, as suicide attempt, happens. (Koskisu & Kulola 2005, 26-34.)

### ***Family burden***

Stress caused by mental health problem in family can be divided into two categories; objective and subjective. Objective stress is related to practical difficulties and everyday challenges. (Koskisu & Kulola 2005, 70.) Lefley (1987) have noticed that families often have same kind of burdens: distribution of work changes in family, money situation is worsening, parenthood and other responsibilities are centered to other parent and relationship with family, relatives and friends are changing. As for Mars (2000) brings forward that also low support and deficiencies in care system but also stigma related to mental health problems, burdens family.

Subjective stress in case when someone in family is suffering from mental health problems, refers to personal feelings and experiences which can be different between family members. Talking about these might feel difficult. (Koskisu & Kulola 2005, 63.)

Marsh (2000) has defined factors related to subjective stress in following way:

- Sadness and feeling of loss. (Family might feel that disorder has obtruded in family and is inhibiting encounter. Feeling of safety endures.)
- Sadness becoming chronic. (Ability to function drops temporarily or decisively and when situation becomes chronic also sadness becomes chronic. Bigger the difference in person who fell ill, more influence it has in whole family.)
- Changing feelings in relation to mentally ill family member's feelings. Feelings of family members and overall action of family is based on mentally ill family member's condition. When he is in better condition, the whole family is and feels hope but worse condition reflects to the family as despair and lower ability to function.)
- Emphatic pain. (Family member is emphasizing mental pain of ill family member and is feeling frustrated with powerlessness.)

### ***Adjusting***

When mental health problems in family are lasting long or even for life, the family is looking for adjustment methods. In their book Koskisu and Kulola (2005, 61-62) are presenting Keydel's three different models of adjustment. Family can either succumb, survive or try to succeed. When family succumbs, they believe that situation is going to get better slowly or not at all. Everyday life is mostly surviving in acceptable level. Future is not considered but the situation is seen as unchangeable. When family is trying to survive, they are mostly looking for solutions to practical, daily problems and living one day at the time. Then before anything, family trying to succeed is reaching for the future. They are trying to take into account the whole family. These different ways to act are not permanent and can change according to families' situations. (Koskisu & Kulola 2005, 61-62.)

### ***Recovery***

Family need to recover in the same way than the family member who had experienced mental health problems. Mental health problem influences in a different way to each family member – experiences of partner differ from experiences of children and so forth. Also recovery proceeds at individual rate, and therefore there might be

many different phases of recovery going on in the family. For that and other reasons, the overall knowledge about recovery process is valuable to the family. Recovery doesn't always advance linearly but same phases can repeat themselves until the person is ready for the next recovery stage. During the process person grows and changes. Also strong feelings are natural part of the recovery process. (Spaniol & Zipple 1994.)

### ***Resilience***

Family's resilience affects to how family copes with difficult life situation. Walsh (2006, 4) defines resilience in following way: "capability to rebound from adversity strengthened and more resourceful." Denham and others (2015, 300.) call resilience "positive way to manage stress". Family is not seem as damaged but capable to survive stressful event successfully. Together family forms a resourcefulness ensemble. (Denham et al 2015, 300.)

Resilient family has many positive characteristics in a moment of difficult life situation. First of all they are adjusting difficult situations and they are communicating well as a family. Resilient family is also showing caring towards each other and is capable to manage conflicts. In the situation they have flexibility what comes to family roles and responsibilities. Lastly they have enriching social connections outside the family. (Denham et al 2015, 301.)

### ***Mental health problem as a crisis***

When family member gets ill mentally, it is a crisis for whole family. The person with mental health problems and rest of the family are experiencing same kind of process when coping with the new, changed situation. Knowing the main things of the process helps understanding the situation. (Omaisiet mielenterveystyön tukena.)

Process is strived to describe by four phased model which are presented in the table below. That is still only a guideline because process itself is really individual. Every stage includes different kind of emotional, intellectual and physical tasks and person

might move back and forth from phase to another conducting unfinished tasks.  
(Spaniol & Zipple 1994.)

Table 1. Phases of recovery process (based on Spaniol & Zipple 1994.)

Phase	Essential content
<i>Discovery / denial</i>	<ul style="list-style-type: none"> <li>-hard to accept the situation</li> <li>-finding other more acceptable explanations</li> <li>-searching answers from every possible source</li> <li>-understating the problem</li> <li>-negative attitudes toward mental health problems</li> <li>-strong disbelief</li> <li>-persistent denial throughout recovery process is possible</li> <li>-relationships inside the family change -&gt; tension, frustration</li> <li>-reality of the disability comes along</li> </ul>
<i>Recognition / acceptance</i>	<ul style="list-style-type: none"> <li>-becoming aware of the mental illness</li> <li>-expectations towards professionals increase</li> <li>-feelings of guilt, embarrassment and self-blame</li> <li>-strong sense of loss</li> <li>-emotional changes caused by cyclical nature of the illness</li> <li>-grieving process begins</li> <li>-questions arising</li> <li>-finding new answers to the questions</li> <li>-family members change profoundly</li> </ul>
<i>Coping</i>	<ul style="list-style-type: none"> <li>-“struggling with a problem without adequate knowledge, skills or support”</li> <li>-coping takes a place from grieving</li> <li>-continuing individual life</li> <li>-consideration of how to support ill family member</li> <li>-coping with everyday challenges and other things related to crisis</li> <li>-distrust against professional</li> </ul>



	<ul style="list-style-type: none"> <li>-hopelessness, despair, pessimism</li> <li>-importance of peer support</li> <li>-managing in daily life with ill family member as focus</li> <li>-possibilities of inpatient care starts to interest</li> <li>-better relationship with professionals</li> </ul>
<i>Personal and Political Advocacy</i>	<ul style="list-style-type: none"> <li>-awareness of ongoing recovery process</li> <li>-feeling different about oneself</li> <li>-changes in family members</li> <li>-less self-blame</li> <li>-increased confidence</li> <li>-some level of acceptance</li> <li>-focusing on necessary things</li> <li>-relationship with professional equalizes</li> <li>-political advocacy arises</li> <li>-willingness to change things</li> <li>-view of life deepens/integrates</li> </ul>

### 3.2 Family mental health nursing

#### **Concept**

Family focused nursing is just one of many terms describing the connection between families and nursing. Clear, unambiguous definition for family focused nursing is still not existing. This definition is also expanding and evolving in time. New theoretical information and practical experiences but also changing policies, society and events are shaping the definition. (Coleman 2002, 3-4.)

According to Wright and Leahey (1990, 148-154) family nursing is implemented by taking into consideration connections between individual person, family, health and sickness in care plan and evaluation of the treatment. As for Friedmann (1992) is dividing the definition of family nursing into three different dimensions; family can be seen as a background but the main focus is in individual. According to Hakulinen and

others (1999, 28) Friedmann (1989) also described this approach as individually focused family nursing.

Second way approaches family as sum of its members. Family is seen as problem or requirement focused unit and by treating parts of health care workers are striving to affect the whole family's wellbeing. In third approach family is seen as a client. This approach highlights the family, individuals are background. Family can be observed from different perspectives; structure, relationships, dynamics, actions and so on. Family itself is interactive unit and there is interaction inside the family but also between family and environment. (Friedmann 1992.)

Hakulinen and others (1999) present that according to Friedmann (1992) these all three methods can be used at the same time or separately. The third approach, family is a client is still highlighted. In order to talk about family nursing, family should at least be seen as a background (Hakulinen et al 1999).

### ***Importance of family nursing***

Regardless of importance of family nursing it often is forgotten when individual care is in strong focus. In care of an infants and children family nursing has been important concept for longer time but when adult is getting ill, the family point of view might more easily be left behind. (Denham et al 2015, 30.)

Importance of family nursing can be justified in many different ways. One essential reason is that family member getting ill affects to the whole family not just the one who is getting ill. Also some illnesses and risk factors that might be possible with other family members as well, influence the whole family. For example the results of gene test might touch the whole family in very concrete way. When family is a part of nursing it is also possible to understand individual's situation from wider perspective. After all, one person can only tell one story. Later the family has important role in recovery of the family member. (Paunonen & Vehviläinen-Julkunen 1999, 17-18.)

### ***Implementation***

Treating a family can be implemented by using several different methods. Common for all those is an aim to improve family's health. Good partnership between health care worker and family requires good interaction. For example, continuity, encounter and respect are also important elements of good partnership. Methods itself can be described by terms guidance, supporting family development and integrity, setting goals or making deals, for instance. (Åsted-Kurki et al 2008, 73-74.)

Family can be seen from resource point of view and by using those can family be strengthened. According to Åsted-Kurki and others (2008) Feeley and Gottlieb (2000) are stating that family's resources can be used in three different ways:

- Charting the resources and giving feedback
- Improving and using resources
- Finding out resources and highlighting them

### ***Psychoeducation***

From the mental health point of view psychoeducation is one essential method which is reaching for increased understanding by using different kind of methods. Psychoeducation can be implemented with individual, family or in group. Anyway the goal is to offload the situation and find common understanding about it. Professional can share theoretical information and family can tell about their own feelings and experiences. The starting point is that there is a mental health problem and that fact is accepted in family. Instead of full recovery the goal might be preventing new relapses and helping family's wellbeing. (Lähteenlahti, 2008.) Increase of understanding and compliance, ways to control the disease, recognizing symptoms and emotional support are important as well. (Kieseppä & Oksanen 2013).

Psychoeducation can be described not only with educational perspective but also with psychotherapeutic point of view. It is not only giving information but also going through issues and feelings in trustworthy relationship. Also hope, looking for the

future and decreasing stigma are strongly related to psychoeducation. (Kieseppä & Oksanen 2013.)

Psychoeducation is not based on strict guidelines and there is no need for special training to implement it. It is desirable that people working with psychotic patients would apply psychoeducation in their work. It is also recommended that every unit working with psychotic patients should define what kind of psychoeducation they are offering. Psychoeducation itself can comprise many different kind of methods. (Kieseppä & Oksanen, 2013.)

Psychoeducation used with other methods is essential part of the treatment of psychosis. With first psychotic episode its role is especially important but it is also established part of rehabilitation over all. For example following are common themes in psychoeducation:

- With the help of **stress-vulnerability model** it is easier to picture the situation and find some exposing factors in person's history. This also aims to eliminate strong mystique around the psychosis.
- The goal of the **revision** is make sure information will be received. Information should be given in reasonable amounts and by using different styles as literature, role playing etc.
- When the acute phase of the psychosis is over **identification and control of the symptoms** is used to recognize early warning signs and symptoms. Also controlling methods are considered are practiced.
- Also improving and practicing **problem solving and communication skills** affects to the person's life positively. (Kieseppä & Oksanen 2013.)

Family and psychoeducation goes well together. Results are showing that it has positive influence on ill family member but also whole family. Importance of family in psychoeducation might also become emphasized when person is having problems with communication and ability to function. (Kieseppä & Oksanen 2013.) Especially in the outpatient care the role of family in care and rehabilitation of the ill family mem-

ber is essential. Ill person is still family member and mental health problem burdens the whole family. It is primarily important to take family into account when treating a psychiatric patient. (Lähteenlahti 2008.)

### 3 Aims and purpose of the study

The aim of this study was to discover how families can be supported when member of a family is having a first episode of psychosis. Study aimed to search practical ways of helping for mental health nurses and other health care providers working with families in which a family member is experiencing the first psychotic episode. The purpose of this study was to provide evidence based information for the practical use.

The research question of this study is:

**How family can be supported when family member is having first psychotic episode?**

### 4 Implementation of the thesis

#### 4.1 Methodology

Interest of qualitative research is something which cannot not easily be measured in numbers, and on the other hand that isn't the aim of literature review anyway. It focuses to topic comprehensively, picturing a real life. Qualitative research can be implemented in multiple different ways. (Hirsjärvi et al 2009, 160-161.)

This thesis is carried out by using systematic approach in literature review. It is not expected that undergraduate or postgraduate student can implement a systematic

review, but general principles and guidelines should still be followed (Aveyard 2010, 16). Systematic approach searches answer to specific question by using existing material about the topic. 'Research on research' definition refers to researching something that someone has already researched. For the same reason this approach can also be called secondary research. It searches, appraises and summarizes existing information to be research review. Word systematic indicates that used material has strict criteria to follow. These parameters help with final material selection. For example setting time-frame for selectable material is one typical way to limit choice of literature. (Paharoo 2006, 134.)

Essential for any kind of research is to familiarize with literature and existing information about the studied topic. All in all, the meaning of literature review is to justify current study, collect existing information, present current research in a context of existing knowledge and highlight the conceptual and theoretical basics about the topic under research. (Paharoo 2006, 127-128.)

## 4.2 Literature search

Search of literature is endless unless inclusion and exclusion criteria for the research material is not defined beforehand. Based on resources the research material is limited to get as relevant and reliable material as possible. There is need for both contextual and temporal demarcation. (Metsämuronen 2006, 37.) Inclusion and exclusion criteria of this certain thesis can be found below.

### ***Inclusion criteria:***

- Published after 2005
- Article is in English or Finnish
- Full text article is available for free
- Article is available online
- The article is an original research
- Responds to research question

- Concerns the first psychotic episode
- Concerns the topic from nurse's or other health care providers, family's or from individual family member's perspective
- Support methods can be related to any kind of psychosis

***Exclusion criteria:***

- Published before 2005
- Full text article is not available for free
- Contains only ill family member's point of view
- Concerns only the effect of family to the ill patient

This criteria was selected to find current, relevant and high quality research material that is answering to the research question. Information was searched from the last ten years (2005-) to outline older information. Content limitations were made to guarantee that the material answers the research question. Lack of financial resources leads to that articles need to be available free of charge.

All of the databases were used through JAMK's Nelli-portal. Used databases were Cinahl (full text), Academic Search Elite (EBSCO) and PudMed. In all searches, it was defined that material can be published earliest by 2005 and article needs to be full text free of charge.

***Database: CINAHL*** (28<sup>th</sup> of October, 2015. January 2008-, full text, peer reviewed)

With different search words (mentioned below) in total 6 articles were found, partly same than from other two databases. Peer review was included in search to increase the quality of researches found.

Table 2. CINAHL.

	Search words	Results	Relevant by title	Relevant by abstract
1.	First psycho* AND family AND support	18	7	5
2.	First psychosis AND family	25	10	5
3.	First psycho* AND family intervention	8	6	4
4.	First psycho* AND family AND psychoeducation	4	1	1
5.	Psychosis AND family AND support	34	12	5

**Database: EBSCO Academic Search Elite** (28<sup>th</sup> of October, 2015. January 2008-, full text, peer reviewed)

Eight articles were found in total, partly the same than in CINAHL and PubMed searches. Search words mentioned in table below. Peer review was included in search to increase the quality of researches found. Peer review was included in search to increase the quality of researches found.

Table 3. Academic Search Elite (EBSCO).

	Search words	Results	Relevant by title	Relevant by abstract
1.	First psycho* AND family AND support	55	11	7
2.	First psychosis AND family	55	17	7
3.	First psycho* AND family intervention	14	7	4
4.	First psycho* AND family AND psychoeducation	7	2	2



5.	Psychosis AND family AND support	671	26	7
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**Database: PubMed** (28th of October, 2015. January 2008-, full text)

In total eight articles were found with the search words mentioned below. Partly articles were same as found in the other databases. Medical point of view was strongly highlighted in this database.

Table 4. PubMed.

	Search words	Results	Relevant by title	Relevant by abstract
1.	First psycho* AND family AND support	4	0	0
2.	First psychosis AND family	215	12	6
3.	First psycho* AND family intervention	1	0	0
4.	First psycho* AND family AND psychoeducation	0	0	0
5.	Psychosis AND family AND support	457	13	4

The first selection was based on the article's title. From 1568 search results 124 were suitable according to the title. The articles were selected if the title included for example following words: family, care giver, parent, sibling, family interventions, family psychotherapy, psychosis, first episode psychosis, psychoeducation, family's experiences or needs, services for families, early intervention or group. In the next stage abstracts of these selected articles were read. At this point it was found out if the article was dealing with first psychosis and needs of the family, not only the needs of family member having psychosis. After all, 57 articles were relevant based on the abstract. Because of the same articles were found with various search words and from different databases and all together 14 different articles were found.

Lastly, all the 14 articles were read to evaluate if they fit in inclusion criteria and answer research question. At this point six articles were excluded. Instead of focusing family's needs and possibilities to help, some articles were more about influences of psychosis in the family and coping methods inside the family. Some articles approached the topic from the family's point of view but still focusing on only the ill family member. One excluded article wasn't original research but more like some kind of recommendation.

To search if there is some additional articles used as a reference in the articles found from databases, the manual search from the chosen articles' reference lists was made. At the first place all the reference were read through and articles with suitable title and correct time frame (published earliest by 2005) were noted. All the same inclusion and exclusion criteria was used when implementing this search. 34 articles were relevant by title and 13 of them also relevant by abstract. In some cases the full text wasn't available in spite of relevance. All of the articles were same than the ones found in database search. The process of this search is described below.

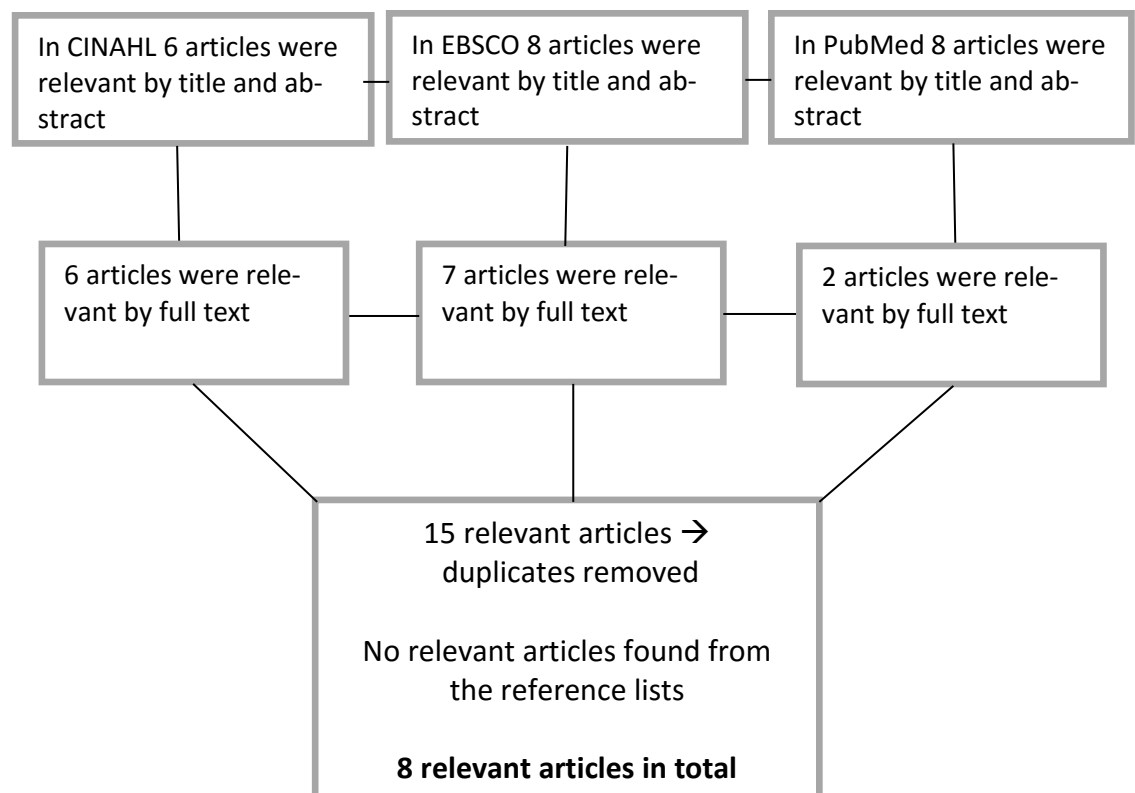
Table 5. Reference lists.

<b>Article</b>	<b>Relevant by title</b>	<b>Relevant by abstract</b>	<b>Full articles found and relevant</b>
Lowenstein, J., Butler, D. & Ashcroft, K. 2010.	9	4	2
McCann, T., Lubman, D. & Clark, E. 2011.	8	2	2
McCann, T. & Lubman, D. 2014.	3	2	0

Nilsen, L., Frich, J., Friis, S. & Rossberg, J. 2014.	3	0	0
Sin, J., Henderson, C., Pinfold, V. & Norman, I. 2013.	8	3	2
Sin., J., Moone, N., Harris, P. 2008.	3	2	2
Sin., J. Moone, N. & Newell, J. 2007.	6	3	2
Sin., J., Moone, N. & Wellman, N. 2005.	0	0	0

After database search and manual search in total 8 relevant articles by the text was included in to the final literature review. The full list of the articles can be found from the appendices of this thesis.

Figure 2. Article selection process.



### 4.3 Data analysis

In this thesis the inductive approach to data analysis was used. It is based on used material without preconceived expectations (Eskola & Suoranta 1998, 19). This qualitative way to analyze data strives to search answer for research question by categorizing contents of used material according to their theoretical meanings. Analyze aims to compact piece of existing knowledge about the topic. (Kylmä & Juvakka 2007, 113.)

Systematically chosen information related to the topic is being sifted with an aim to find relevant information about the topic (Kylmä & Juvakka 2007, 115). Kylmä and Juvakka (2007, 116-120) present that according to Kyngäs and Vanhanen (1999) there is a threefold way to approach inductive data analysis: simplification, grouping and abstraction. First there must be overall picture about the material used. According to the model of Kyngäs and Vanhanen, the first stage of analyses includes condensing relevant information by still remaining the original meaning. Grouping aims to gather contextually similar expressions into groups. Grouping can be continued to subcategories and general categories based on the aim of specific research in progress. Each category is named. The third stage, abstraction, is already being touched on previous stages of data analyses. The whole data analyze strives towards abstraction until there is a possibility reach overview according to the basis of inductive approach. (Kylmä & Juvakka 2007, 116-120.)

At the first stage all the chosen articles were familiarized briefly. During the second reading the articles were combined with simple words (=simplification). Such as information, peer support etc. After that small words had been used to combine different articles, the aim was to divide topics into rational and clear categories (=grouping). Abstraction was made through the process to make sure that each category answers to research question.

Table 6. Data analysis process.

Mental health professionals	Family centered attitude	How family can be supported when family member is having first psychotic episode?
Family friendliness	Observing needs of the family	
<i>Carers</i>		
Siblings		
Psychoeducational groups	Implementing psycho-educational methods	
Knowledge and education		
<i>Written information</i>		
<i>Modern methods</i>		
Peer support		
<i>Sharing experiences</i>		

## 5 Results

### 5.1 Family centered attitude

#### ***Role of the mental health professionals***

Mental health professionals are in the key role in supporting the family of person with first episode psychosis. Approachable, supportive, informative, helpful and interested are the words that carers are using when describing a good mental health professional. “Simply being there and offering opportunities”, said one participant in McCann’s and others’ study when talking about accessible and supportive professionals. It is important that family members feel that professionals are there for them also and they can approach them with confidence. Being listened and taken seriously is essential. Professionals should also provide supportive environment. It was seen as a negative side if professionals were hard to reach or not responding in timely manners. Some also felt that professionals undervalue their contributions, don’t listen or take them seriously. (McCann et al 2011.)

It is important that there is an opportunity to be involved in the treatment and gain information about the ongoing process. With the help of accurate information it is easier for the families to explain the situation for the other close people, as friends. (McCann et al 2011.) In the research of Nilsen et al (2014) participant highlighted that the opportunity to listen “skilled, professional, health providers” was crucial. In the same research that explored families’ experiences of psychoeducational family interventions, participants connected following things with good group leader (=mental health professional); involved, honest, open-minded, supportive, capable of disagreeing and sharing issues from own life (Nilsen et al 2014).

In research of Sin and the others (2005) one responder (carer) said: “Nobody ever asks about us.” Possibility to talk with the professional was brought out also by the siblings in research of Sin and the others (2008). In the same research it was discovered that possibilities for that are still poor. Some highlighted that possibility to care meetings with all the people involved in the treatment is essential. (McCann et al 2011).

## 5.2 Observing needs of the family members

### ***Family friendliness***

The family approach in care of the first episode psychosis should be taken into consideration by evaluating individual needs of the family members and offering them change for contact routinely. It is still not obvious that family-inclusive services reach all the family members. (Sin et al 2008.) In case family refuses for the services, that should be understood. Offering possibilities later on and pondering alternative services is also desirable. (Sin et al 2007.)

### ***Caregivers of person with first-episode psychosis***

Caregiving role falls to parents when many of the people experiencing their first psychosis are still quite young and still living in their parental home. It is obvious that caregivers carry a lot of responsibility in care of young person. (Sin et al 2007.) In the

study of the Sin and others (2005) carers of young people with first-episode psychosis told that they are in the between of their dependant and mental health services. Some said that they are feeling that they are invisible for mental health services. Feeling of taken for granted also occurred when carers were excluded from the treatment. (McCann et al 2011.) It would be important for them to receive support and information in the early stage of first psychosis when the psychological distress is at its highest. Carer-friendly, understandable information even just about the basic things and coping methods would be appreciated. (Sin et al 2005.) It is also possible that carer needs information about the possible financial support (Sin et al 2007).

In their study Sin and others (2007) presented the separate care pathway planned for the carers in Berkshire, England carried out in cooperation with statutory and voluntary services. Changes (mobilization, expanding and development) in services very made based on earlier study about carers' experiences and needs. They have found out that from the carers' but also mental health professionals' point of view it easier to point out available services for the carers in the stressful life situation when most of the attention is in person actually having psychosis. Later on it is possible that carers are lacking the capacity to seek help for themselves. Care pathway has three steps; (i) first contact and identification, (ii) assessment and information giving and (iii) effective service response. After carer is identified it not that likely to be left unsupported. During the pathway it is essential to assess carer and offer suitable services as information pack, psychoeducation and both individual and group meetings. (Sin et al 2007.)

### ***Siblings of person with first-episode psychosis***

In the research of Sin and others (2008) sibling experiences and needs were explored. What comes to services many of them felt that many services for the family members were designed for the primary caregivers of the person having psychosis. Some who search for help felt themselves a minority group among caregivers. Siblings' needs were not taken into consideration that well. Some felt that there is no appropriate services directed for the siblings where they can talk about difficult feel-

ings without their parents being present. Some were afraid that talking about their concerns would cause further pressures for their parents. (Sin et al 2008.)

From the services point of view it would be important to recognize the needs of this group also. In addition to that services should be accessible and flexible. They would value information accessible in variety of formats, opportunity to discuss, peer support group and education about communication skills and coping methods. Siblings didn't see themselves as primary caregivers but they thought that knowledge would assist them to maintain and even improve the relationship with their sibling having psychosis and to support that person better. (Sin et al 2008.)

Sin and others (2008) present that voluntary, statutory and youth-focused organization should in cooperation develop services for the siblings. Psychoeducation, support groups, education and other interventions developed for the siblings are examples of the services for the siblings of person with first psychotic episode. The main idea is that the unique needs of siblings should be taken into consideration. (Sin et al 2008.)

### 5.3 Implementing psychoeducational methods

#### ***Different kind of psychoeducational groups***

Psychoeducation for families are implemented in single-family and multi-family groups. It depends on each family which is suitable for them. In the study of Nilsen and others (2014), concerning families experiences of psychoeducational family intervention one participant said: "It is so personal; I won't share it with anyone." That is obviously poor premise for multi-family group sessions. Some thought that fewer people in the group would have eased the talking more openly. One participant brought out that in the beginning it would be easier to have single-family meetings to aim to talk more openly inside the family. On the other hand some participants reported that sharing struggles with other families was helpful. (Nilsen et al 2014.) There are groups for more specific groups also. One possibility is cognitively orien-



tated carers' group for the carers' of young person with first episode of psychosis. (Lowenstein et al 2010).

In the research on Nilsen and others (2014) families participated in 2 year lasting psychoeducational intervention. It lasted for two years including joining in phase, survival skills workshops and structured meetings every other week. (Nilsen et al 2014). Sin and others (2007) presented that each of the meetings with multi-family groups was divided so that the first phase included information about the day's topic and in the second phase it was possible to talk about personal experiences in smaller groups led by group facilitator. The study of Lowenstein and others (2010) concerned the efficacy of cognitively oriented carers' group. Topics of their sessions were for example: stigma, rights of carers, psychosis, medication, mental health services, coping, abuse of alcohol and drugs, carers' wellbeing, communication, financial issues, future planning and so forth. (Lowenstein et al 2010).

Sin and other (2007) pointed out that services should take into consideration the special needs of families experiencing first psychotic episode. For example relapse prevention might be frightening for the people who are just going through their first psychotic episode and acceptance of the whole situation is still ongoing. It is also important to remember that at this point many are not having any formal diagnosis (yet) and psychiatric terms overall might cause fear. (Sin et al 2007.) In the below the elements (knowledge and education, peer support, chance for a conversation) that are possible or even recommended in psychoeducation also, are presented more specifically.

Family members who did not experience psychosis themselves very ready to participate psychoeducation group from the day one but at the same time there was an understanding that for the one who is having psychosis it might not be possible. It is still important to take in to consideration that family members would often prefer getting information in very early stage. When participating family group intervention the feeling of involvement was important for the family members. The ones having

psychosis, on the other hand, often participated in groups because of their family or because of involvement to the recovery process. (Nilsen et al 2014.)

Although participating in psychoeducational family intervention was described as debriefing procedure, the intervention was still experienced hard and feelings of anxiety and tension appeared in participants. Some were experiencing insecurity through the process while some reported that it eased over the time. The clear structure and time frame supported the implementation of the process. For the participants it was important that they could talk openly in confidential situation about the difficult issues they were going through. One participant said: “I remember looking forward to bringing in themes to talk about in the meetings, themes I could not talk about with [patient] alone.” When time went by it became easier to talk about the difficult issues – this also made environment more secure. Family intervention also eased feelings of shame and offered the ones with psychosis empowerment. (Nilsen et al 2014.)

### ***Knowledge and education***

Carer participants in the research of Sin and others (2005) said that even general knowledge about the psychosis would be important for them. Coping skills, details about symptoms and typical challenges were also seen as practical information for the carers (Sin et al 2005). Learning more about those was important for overall coping of family members (Nilsen et al 2014). In a research of Sin and others (2008) siblings of persons with first psychosis said that that brief and phase-specific information would be welcomed. They also hoped education on communication and coping skills. They wanted to know how to support their siblings with psychosis and how to cope with their symptoms and behavior. Fear of not acting “right” and effecting negatively to their siblings was brought out. (Sin et al 2008.)

Many families with first-episode psychosis have experiences of alcohol and street drugs. In the study of Sin and others (2007) it was told that in local services there is also special session related to cannabis, alcohol and street drugs use within the

young people with psychosis. This session was kept by actual drugs worker to increase the practical point of view. (Sin et al 2007).

There are many benefits of knowledge and education. It can ease the pain and guilt and also assist the more realistic image about the psychosis. One family member with psychosis said:” I gained knowledge about fiction and reality and that I might have mixed them up during a psychosis.” For those with psychosis the information seemed also decrease fears and increased the plan making for future. Some reported that psychosis seemed more harmful after education. Understanding stress-vulnerability model helped families to appreciate the need of sufficient recovery time. Knowledge overall made them capable to value small things in daily life instead of thinking how the life would be instead of psychosis. (Nilsen et al 2014.)

Some feel that they are lacking the appropriate information. For example, although carers play major role in young person’s life and they often have many responsibilities related to the treatment and rehabilitation, they still often felt left outside (Sin et al 2005.) For example only six out of eleven carers in the interview of Sin and the others (2005) could not name their children’s diagnosis nor describe the overall treatment. The carers search information by themselves from the internet and books but often the information was conflicted in various sources and the level of information wasn’t appropriate (Sin et al 2005).

### *Written information*

McCann’s and Lubman’s (2014) research explored caregivers’ experiences of problem-solving guided self-help manual. Sin and others (2007) told about carers’ information pack as a part of care pathway to carers of person with first psychosis. Sin and others (2007) suggested that information pack is given to carers in that early stage that they have opportunity to discuss about it later on with mental health professionals – it was seen as dialogue opener.

Among the carers written manual was experienced to be good although some modifications were hoped. Carers felt that manual was accessible because it offered information in clear and understandable form. It could also be read in any place and used in practice also. Manual included information about the psychosis, carers' well-being, coping methods, services, ways to support well-being of psychotic person and handling effects of the illness. (McCann & Lubman 2014.) In information pack in the study of Sin and others (2007) included overall knowledge about mental illness, medications and practical advises. In addition to the information pack some literature and carers' own experiences about this specific life situation was introduced. Carers were hoping that information about the psychosis would concern especially first episode of psychosis which partly has its own characteristics. Importance of telling about carers' rights and services was also valued. (Sin et al 2007.)

The main focus of the manual in McCann's and Lubman's research was to promote well-being of the carers'. One participant commented: "It teaches me how to deal with myself first." It is important to pay attention to the people supporting person with first episode of psychosis and aim to maintain their wellbeing and teach new coping methods for the totally new situation. (MacCann & Lubman 2014.) In the study of Sin and others (2007) it was reminded that natural feelings of grief, loss and guilt should also be concerned. For the carers it was important that manual didn't only provide factual information but also practical strategies and help for problem solving in daily life with person having psychosis. Manual included so called problem solving tool which aimed to develop coping methods of carers. Overall, manual also helped them to understand youngsters with psychosis better. (MacCann & Lubman 2014.)

Although manual was presenting realistic case studies which revealed other people in the same kind of situations, the non-existence of peer support was seen as a negative side. "I find it a lonely experience", one carer said. Carers also highlighted that for some written information is not pleasing. (MacCann & Lubman 2014.)

### *Modern methods (DVD, online)*

Some families reported that good form of giving information and support would be via DVD. Some people who don't prefer reading, for example, could benefit from that. It was thought that in form of the film the information would be easy to watch with whole family and discuss about it after wards. Some participants of the research thought that given literature together with DVD and online formats would be good combination. (McCann & Lubman 2014.)

Online form was highlighted because of its accessibility. For example online discussion forums for carers would be one possibility. (MacCann & Lubman 2014.) Siblings of brothers and sisters with first psychotic episode reported that easy access to information is important and for example web sites would be preferred (Sin et al 2008). Based on E Sibling project Sin and others (2013) presented the online intervention for sibling that consist three sections: psychoeducation, peer support and resource links. Online intervention would be updated and led by professional. Young people would have easy access to the secured pages. In psychoeducational part information would be provided but also a chance to ask for the experts. Relevant information from other sources would be provided also. Peer support would mean sharing and receiving support from the peers in the same situation. Discussion would happen through moderated discussion board. (Sin et al 2013.)

On the other hand some were still concerned that not everyone still has computer and access to the internet. Either internet itself is not necessarily yet familiar and easy to use for everyone. (McCann & Lubman 2014.)

### ***Peer support***

Meeting with the people in the same kind of situation was seen important. The feeling of being supported and to support others but also the possibility to open up about the daily struggles was important. There is a sense of belonging and mutual support between the people going through the same kind things. Some felt less alone. (Nilsen et al 2014.) Some felt peer support essentially important because it

was hard to reach professionals from the mental health services (McCann & Lubman 2014). For some the realizing that some are suffering from more severe difficulties than their own family member was encouraging (Nilsen et al 2014).

Those participating in the research about problem-solving guided self-help manual, found that good but lonely experience. What they would have needed in addition to the manual was some kind of peer support group with whom they could discuss about the topics in the manual. (McCann & Lubman 2014.)

Travelling and long distances were kept as a barrier for face-to-face group conversations. Difficulties in arriving to certain place was seen problematic. (McCann & Lubman 2014.) Siblings of psychotic persons' suggested that there could be some kind of hotline to contact other siblings in the same situation when there is a need for peer support (Sin et al 2008). As a negative side of peer support groups some were afraid that participation to these kind of groups would make them more vulnerable when they are identified as carers of person with first psychotic episode (McCann & Lubman 2014).

### *Sharing experiences*

Sharing real life experiences with the persons who have been in the same situation was evaluated to be really essential. Gaining new perspectives was one of the good sides of the sharing experiences. Also when family members get some practical information about the topic it effects positively to their attitudes towards the one having first-episode psychosis and increased their understanding. (Nilsen et al 2014.) Sharing experiences also decreased the sense of burden (Sin et al 2007). The ones having psychosis evaluated that family members receive valuable information by hearing real life stories and for themselves it was emotionally difficult to hear about other people's problems but still it increased the hope. For some the sharing is not an option at all. Issues related to psychosis can be seen too personal to share. (Nilsen et al 2014.)

## 6 Discussion

### 6.1 Thoughts about the main results

This thesis aimed to find ways to support families experiencing their first psychotic episode. Although some factors, described more precise below, weakened the reliability of this study, many essential suggestions were provided. The purpose of this thesis was fulfilled since it managed to explore the support needs of the families in case of first psychosis. This thesis presented the possibilities to support families in service level generally but also from individual nurse's or other health care provider's or from single work community's perspective. Since most of the researches used in this literature review approached the topic from the families' point of view, this thesis gives valuable information about the support needs of the families from their own perspective.

Main results were that care should be based on family friendly attitude by the professionals and individual needs of the family members should be taken into consideration. As a psychoeducational methods results brought out psychoeducational groups, information and education and peer support. These results show that the need of support arises from the very basic level. Already in planning and implementing services family should be taken into consideration. Realization of the unique needs of the families experiencing first psychosis should be noted already at this point. Researches showed that in this field there is possibilities to improve.

Ways to support families in this thesis are concrete and it is even possible for nurses or health care providers to use those from their own initiatives without any major changes in the work community. For example, providing information might be small thing for a nurse but for families it means a lot. On the other hand psychoeducational groups and possibilities to receive peer support might require bigger changes in work community and even in service level.

As family is important social network, it has an influence on individual's health, getting sick and also recovering. It is inescapable that family affects to family members and family members affect to family. (Larivaara et al 2009, 20-21.) Mental illness is unwanted and unexpected crisis – it has an influence in whole family. Spaniol and Zippel (1994) described that families are going through the same kind of crisis as the one having psychosis starting from denial and ending in personal growth. In the research of McCann and others (2011) some participants (carers) said that they are feeling that professionals undervalue their contributions, don't listen or take them seriously. Actually involvement would be important to the family members (McCann et al 2011).

Seikkula and Alakare (2004) are presenting the "open dialog –model" in Keroputaa Hospital, Finland. Their social network based treatment is different kind of approach to psychiatric treatment and has gained some good results over the years. It is based on the crisis approach and communication between health care workers and families are highlighted. For example, in case of involuntary hospital treatment the social network is invited to the multi-professional care meeting within the first 24 hours. Resolution of psychotic symptoms is not waited but the family is involved from the beginning. Care is planned together with this care multi-professional care group with help of family. It is assumed that dialog and multiple perspectives enriches the treatment. Meetings can be organized intensively according to patient's and family's needs. Families are given an opportunities to involve in process and express their experiences and feelings. Over all social relationships of the patient are seen as a positive resources not as a reason for the problems of the patient. (Seikkula & Alakare 2004.)

Based on the wishes of families results of this thesis showed that mental health professionals should be supportive also towards family members of the one having psychosis (McCann et al 2011). One essential thing that didn't raise so strongly in this thesis is the strong stigma related to mental health problems and attitudes of the



health workers towards the mentally ill patients and their families. Canadian Mental Health Commission state in their report “Opening Minds” that people who are experiencing mental illnesses are feeling stigmatized by health care professionals. They feel disrespected and discriminated and seek of help might happen later. Same report refers to several researches by saying that stigmatizing behavior of health professionals is often unintentional and cause of unawareness. Many problems related to stigma of health care workers include negativity in prognosis and attitudes, lack of knowledge, diagnostic overshadowing, negative attitudes and stereotypes and marginalization. (Mental Health Commission of Canada 2013.)

Stigmatizing behavior of the professionals might be surprising but still it needs to be taken seriously since it is essential that people seeking help for their mental health problems doesn’t feel unwelcomed among the health services. As stigma is hard thing to carry for the one having mental health problems but also to the whole family, health care professionals’ role is to support them and help relieving the sense of being stigmatized, not letting stigma related to mental health problems to affect how to who they treat the patient and the family. Open Minds reported stated descriptively: “—living with stigma is worse than the illness itself.” (Mental Health Commission of Canada 2013).

One of the most essential results of this study concerned the psychoeducational family work as a form of support. Psychoeducation has a great importance in the psychiatric rehabilitation (Lähteenlahti 2008, Kieseppä & Oksanen 2013). According to Kieseppä and Oksanen (2008) every health care provider and unit working with people experiencing psychosis should apply psychoeducation to their work and to define how psychoeducational approach is used in their working place. Finnish Current Care Guidelines of schizophrenia (2015) say that psychoeducation should be part of good care of every schizophrenia patient. It has many benefits for the family member who has psychosis and strong evidence proves that psychoeducation implemented with the family is effective (Skitsosfrenia: Käypä hoito -suositus 2015). Effectiveness of cognitively orientated carers’ group was measured by Lowenstein and others (2010)

by using different measures. Results showed that carers' burden, appraisal of the impact of psychosis decreased (Lowenstein 2010). According to Sin and others (2014) families experienced that alliance, support, knowledge and real life experiences made psychoeducation a good but occasionally difficult experience.

Siblings of the individuals with first psychotic episode mentioned that support could be offered via websites (Sin et al 2008). Also carers in the study of McCann and Lubman (2014) agreed that online or DVD would be option for more traditional methods. Especially internet is an essential part of the everyday life nowadays. There is still people who don't have changes or knowledge to use it but especially for the future generations it will be crystal clear that internet is used in daily basis. To meet the needs of the families now and in future, it is important that mental health services keep pace with development of the society. Also from resources' perspective different kind of self-help methods in online or some other form are important development steps. Internet is full of unsuitable and false information and that means that importance of providing reliable information already exists when people are more and more searching information themselves. Some relevant sources on the other hand offer information that is not that understandable for "normal" people (meaning not health care professionals).

Example of quite extensive online service in Finland is a website called Mielenterveystalo.fi which is provided by hospital district of Helsinki and Uusimaa. It provides trustworthy information for both health care professional and people having mental health problems themselves or in a family. There is information about the mental illnesses and services, self-help guides and tools for self-evaluation. Even online therapy is possible via their website with physician's referral. (Mielenterveystalo.)

## 6.2 Reliability and ethical considerations

By retelling several different researchers Kylmä and Juvakka (2007, 127-128) have defined that credibility, dependability, reflectiveness and transferability are the reli-

able criteria for qualitative research. Researcher should strengthen the **credibility** of the research by using different methods but also evaluate the realization of it in research. (Kylmä & Juvakka, 2007, 128). In this thesis the credibility was increasing when all the chosen articles could be found in at least two different databases. All the articles in the final results were peer reviewed and that partly increases the quality of the chosen articles. The amount of the information was still limited since the chosen point of view. More information could be found about supporting family in case of psychosis or other serious mental health problems. Because this study was especially interested about the special needs of the families experiencing the first psychotic episode some relevant ways to support families might have been excluded. It was also notable that some same researchers were involved in multiple researches. This might affect the credibility of this literature review but because the amount of information suitable based on the inclusion and exclusion criteria was limited, all the relevant articles must have been used.

Results are mostly based on the experiences of family members. Perspective of mental health professional is not strongly presented. This can be seen as both negative and positive side. On the other hand it is really important to be aware of the experiences and needs of the families but it would be essential to have knowledge about the actions and perspectives of mental health professionals also. It is also possible that lack of financial resources in making of thesis excluded some relevant articles about topic.

It is notable that over half (five out of eight) of the articles were made in Britain. For that reason the results are in a strong context of British mental health services and their ways to implement mental health services for the families. Another three studies were made in Australia or in Norway. Although research question was not culturally focused it is clear that this research gives results highlighting strongly the point of view of Western countries. Probably same kind of researches done in African countries or somewhere else in developing countries would give different kind of results.

Kylmä and Juvakka (2007, 129) are presenting that according to Yardley (2000) **dependability** refers to that research process can be followed based on researcher's description. What comes to qualitative research it is still important to remember that same material doesn't always lead to same outcome within different researchers (Kylmä & Juvakka 2007, 129). Inclusion and exclusion criteria, as strict as possible, were set to make chose of the articles as transparent as possible. The aim was also to describe the data search, selection and analysis as well as possible but still it is just one person's point of view and although the literature search were made by following the basis of the systematic approach, the perspective is still based on single person.

According to several different sources **reflectiveness** in research process means that researcher identifies his own premises. It is essential to ponder how researcher himself is affecting to the material he has and the research process over all. (Kylmä & Juvakka, 2007, 129.) In this case the inexperience of the researcher has decreased the reliability of the research. When doing thesis for the first time, the inexperience can lead to mistakes in scientific practice. Still mentoring during the process is helping in carrying out the research.

Kylmä and Juvakka (2007, 129) tell that according to Lincoln and Cuba (1985) **transferability** requires enough knowledge about implementing the research so that it would be possible to evaluate how the knowledge can be applied in the future. What comes to this thesis its transferability mostly occurs in how this information can be used and exploited in the practice. From that perspective this thesis gives some valuable information. Results approach the research question from the service level while it also presents concrete support needs of the families with first psychosis.

Research ethics are concerning both ethics inside the scientific community and beyond it. Ethics inside the scientific community include, for example rule that results of the research can be trusted not to be forged or fabricated. Interest behind the

research and its affect to what is researched and how are examples of ethics beyond the scientific community. (Mäkinen 2006, 13-14.) Kuula (2011, 25-26) presents that according to Merton (1938 & 1942) these four norms are the base of scientific ethos: universalism (background of the researcher doesn't affect to the acceptance of the research), communism (results of the research need to be public and accessible, research is transparent), altruism (despite of personal benefits and authority, new scientific information is searched) and systematic suspicion (conclusion is done when there is enough empiric base). Because of this thesis was carried out as a literature review ethical considerations might not be as comprehensive. Considering credibility, dependability, reflectiveness and transferability in the implementation of this thesis concerns the ethical issues as well by evaluating the reliability of the thesis.

### 6.3 Further research ideas

It was surprising that more articles could not be found based on the resources and criteria of this study. The field of family work in case of especially first episode of psychosis is still quite unexplored area. Many of the researches concern especially influences of first psychosis to the family or family work in serious mental health problems in general but concrete ways to support family in first episode of psychosis is not that highlighted in the current researches. For this reason it would be important that in the future this field would be researched more overall.

Most of the studies approached the topic from the caregivers' or siblings' perspectives. None of the researches were especially concerned about the support needs of the children's of the parent having first psychotic episode. But as mentioned earlier, the most common age for first onset of psychosis is at early twenties. Many don't have children at that point of the life so that must be affecting to the lack of researches also. Still it would be important to explore the special needs and experiences of children in this situation since first psychosis is definitely frightening and even traumatizing experience for the family members.

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## Appendix

Author(s), publishing year	Title	Aim	Participants and intervention	Essential results	Type of research
Lowenstein, J., Butler, D. & Ashcroft K. 2010.	The efficacy of a cognitively orientated care's group in an early intervention in psychosis service – a pilot study	To explore the effectiveness of cognitively orientated group for carers of persons with their first psychotic episode as a part of early intervention.	18 carers who attended at least 10 out of 12 times to cognitively orientated carers group. The effectiveness was evaluated with five different measures (ECI, CBI, BAI, BDI and GTM).	Negative appraisal, feelings of burden, depression and anxiety rates of carers' decreased.	Qualitative: pilot study
Nilsen, L., Frinch, J., Friis, S. & Røssberg, J. 2014. U57	Patient's and family members' experiences of a psychoeducational family intervention after first episode psychosis: Qualitative study	To figure out how patients and their family members experienced psychoeducational family intervention.	12 patients and 14 family members were interviewed. All of the patient's had experienced their first-episode psychosis and participated psychoeducational treatment within the last 12 months. Patients chose the family member	Good alliance was experienced as important thing, as support that families were both receiving and giving to others. Feelings of anxiety might be higher in the beginning of the intervention. Education was useful and real	Qualitative: semi-structured interviews

			they wanted to participate in research.	life experiences were experienced to be good. Participants liked that there was a time limit and structure for the each meeting and intervention over all.	
McCann, T. & Lubman, D. 2014.	Qualitative process evaluation of a problem-solving guided self-help manual for family carers of young people with first-episode psychosis	To search opinions of primary care givers' of young person with first-episode psychosis about the usefulness of problem solving guided self-help manual.	In total 124 carers participated either normal treatment of problem-solving guided self-help intervention. Participants using manual received phone calls weekly to assess treatment adherence. After the research random sample (24 carers) of participants using manual were interviewed.	Guide helped carers to pay attention to their own well-being, increased the knowledge and ways to support young people with first psychosis. Manual was well by its accessibility but more options besides the written version was hoped. Reading manual was felt to be lonely experience and some peer support was demanded.	Qualitative: randomised controlled trial
McCann, T., Lubman	Primary caregivers' satis-	To explore experi-	Twenty first-time pri-	Two main theme	Qualitative: semi-

D. & Clark, E. 2011.	faction with clinicians' response to them as informal carers of young people with first-episode psychosis: a qualitative study	ences of young people with first psychotic episode about how mental health staff responds to them.	mary carers of the young person with first psychotic episode interviewed.	arose from the results; some felt that health care professional are being approachable and supportive but some also reported that they are feeling undervalued as a carer.	structured interviews
Sin, J., Henderson, C., Pinfold, V. & Norman, I. 2013.	The E sibling project – explanatory randomised controlled trial of an online multi-component psychoeducational intervention for sibling of individuals with first episode psychosis	To develop and evaluate the effectiveness of online multi-component psychoeducational intervention for siblings who's brother or sister is having first psychotic episode.			Qualitative: factorial designed RCT
Sin, J. Moone, N., Harris, P. 2008.	Sibling of individuals with first-episode psychosis – understanding their experiences and needs	To explore the needs and experiences of siblings of person with first psychotic episode.	Ten siblings (aged 16-35) of persons with first-episode psychosis were interviewed by using semi-structured model.	Family member's psychosis influenced in siblings in emotional level, changed relationships in the family, brought out variety	Qualitative: phenomenological approach

				of coping methods and enabled some positive changes in family or in individual. Knowledge about the illness, coping methods and communication skills and peer support was hoped.	
Sin, J., Moone, N. & Newell, J. 2007.	Developing services for the carers of young adults with early-onset psychosis – implementing evidence-based practice on psychoeducational family intervention	To describe family-inclusive approach in early intervention in psychosis service in England, Berkshire.			Qualitative study: phenomenological study
Sin, J., Moone, N. & Wellman N. 2005.	Developing services for the carers of young adults with early-onset psychosis – listening to their experiences and needs	To explore the needs and experiences of carers of young adults with early onset of psychosis and to develop local mental health services.	11 carers of young males experiencing their first psychosis were interviewed.	Carers' are having lots of responsibilities in the care of their son with first psychosis. Still amount of information provided is low and they felt as "silent partners in care".	Qualitative: semi structured interviews

